Distress Screening – Moving Beyond Recommendation to Action

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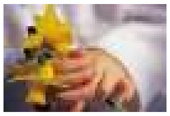

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Objectives

- Review impetus for distress screening and current national recommendations
- Discuss opportunities to enhance distress screening in practice

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A few questions…

You…

- What is your earliest memory of being distressed?
- What does distress feel like to you?
- What is your most memorable moment of being distressed?
- What keeps/prevents you from being distressed today?

Your Patients…

- What does distress mean to your patients?
- What is the patient perception of living with a chronic illness such as cancer?
- How do you identify distress in your clinical setting?
- What resources do you have to manage patient distress?

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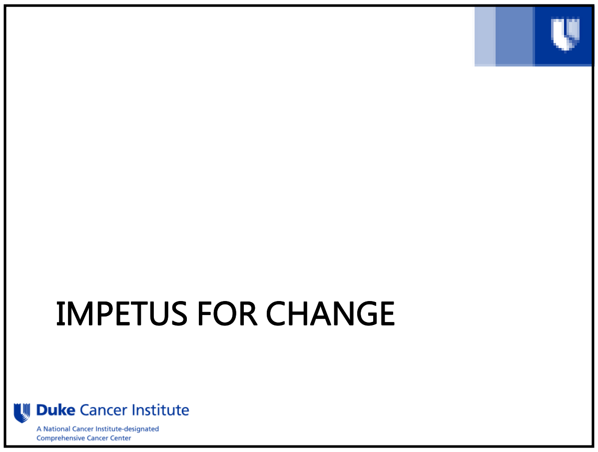

IMPETUS FOR CHANGE

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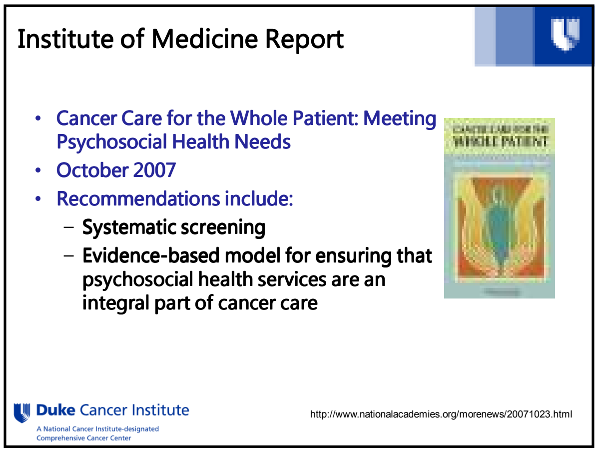

Institute of Medicine Report

- Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs
- October 2007
- Recommendations include:
  - Systematic screening
  - Evidence-based model for ensuring that psychosocial health services are an integral part of cancer care

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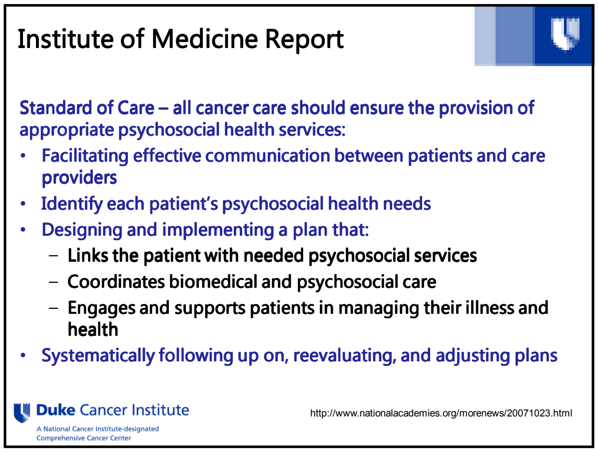
http://www.nationalacademies.org/morenews/20071023.html



Institute of Medicine Report

Standard of Care – all cancer care should ensure the provision of appropriate psychosocial health services:

- Facilitating effective communication between patients and care providers
- Identify each patient's psychosocial health needs
- Designing and implementing a plan that:
  - Links the patient with needed psychosocial services
  - Coordinates biomedical and psychosocial care
  - Engages and supports patients in managing their illness and health
- Systematically following up on, reevaluating, and adjusting plans

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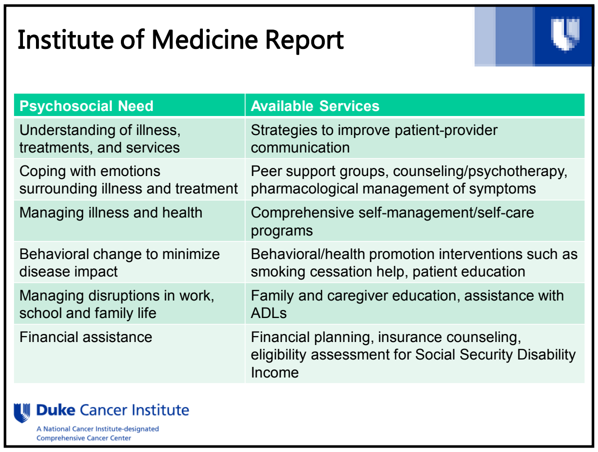
http://www.nationalacademies.org/morenews/20071023.html



Institute of Medicine Report

Psychosocial Need	Available Services
Understanding of illness, treatments, and services	Strategies to improve patient-provider communication
Coping with emotions surrounding illness and treatment	Peer support groups, counseling/psychotherapy, pharmacological management of symptoms
Managing illness and health	Comprehensive self-management/self-care programs
Behavioral change to minimize disease impact	Behavioral/health promotion interventions such as smoking cessation help, patient education
Managing disruptions in work, school and family life	Family and caregiver education, assistance with ADLs
Financial assistance	Financial planning, insurance counseling, eligibility assessment for Social Security Disability Income

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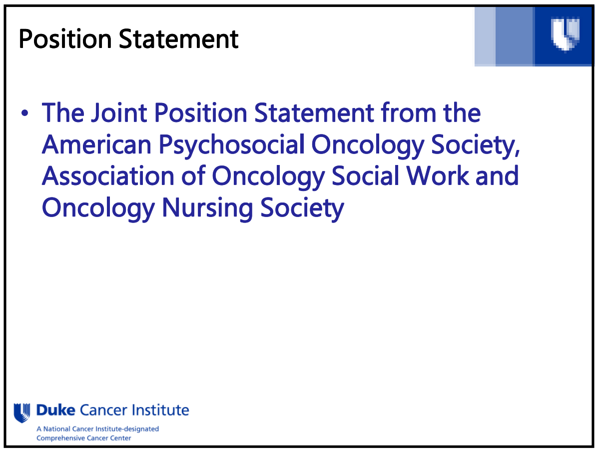

Position Statement

- The Joint Position Statement from the American Psychosocial Oncology Society, Association of Oncology Social Work and Oncology Nursing Society

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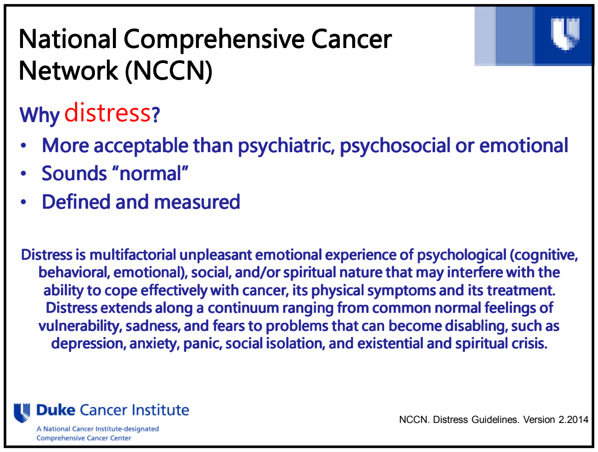

National Comprehensive Cancer Network (NCCN)

Why distress?

- More acceptable than psychiatric, psychosocial or emotional
- Sounds "normal"
- Defined and measured

Distress is multifactorial unpleasant emotional experience of psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

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NCCN. Distress Guidelines. Version 2.2014

National Comprehensive Cancer Network (NCCN)

Standard of Care

- Recognized, monitored, documented and treated
- Screening to identify level and nature
- Initial visit, appropriate intervals, and as clinically indicated
- Managed with clinical guidelines
- Education and training for health care professionals
- Availability of appropriate staff
- Reimbursement for mental health services
- Outcomes measures
- Integral part of care
- Part of quality improvement pan

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NCCN. Distress Guidelines. Version 2.2014

NCCN Distress Screening Tool

- National Comprehensive Cancer Network (NCCN) - Distress Screening Tool
  - Patient completes
  - Practical problems
  - Family problems
  - Emotional problems
  - Spiritual/religious concerns
  - Physical problems
  - Overall numeric score using a 0-10 thermometer

The Tool

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NCCN. Distress Guidelines. Version 2.2014

Survey of NCCN Institutions

- N = 20 of 22 NCCN Centers
- Results
  - 14 of 20 conduct routine distress screening of which 11 rescreen
    - Not screening d/t resources, pilots, commitment
    - 5 screen inpatients routinely
    - 12 screen outpatients routinely
      - 6 all outpatient populations
      - 6 only certain populations
  - 19 of 20 have mental health service available
  - Triage
    - 1 automatic, 12 review and then refer, and 1 uses both
    - Social work, psychology, psychiatry, and chaplaincy
  - Of those screening, methods used
    - 2 interview, 9 self report measure, & 3 interview and self report
    - 5 use Distress Thermometer only, 2 DT and other self report, and 5 use other self report

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Donovan KA & Jacbosen PB. (2013). *JNCCN*, 11.

American College of Surgeons – Commission on Cancer

- Online February 28, 2013
- Standard 3.2, Psychosocial Distress Screening, is a new 2012 Standard and must be phased-in for 2015
- All cancer programs will need to demonstrate that they screen patients diagnosed with cancer and identify the issues that can negatively impact treatment and outcome
- Entire team involved
- Evaluate Cancer Committee annually
- Video

https://www.facs.org/quality-programs/cancer/coc/standards/video/chap31/chap32

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Standard 3.2 Psychosocial Distress Screening

- The Cancer Committee develops and implements a process to integrate and monitor in-site psychosocial distress screening and referral for the provision of psychosocial care
- Purpose of the standard is to "develop a process to incorporate the screening of distress into the standard care of oncology patients and provide patients with identified distress with resources and/or referral for psychosocial needs"
- Timing of screening, method, tools, assessment & referral, and documentation

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Wagner, LI., et al. (2013). *JNCCN,* 11.

Oncology Care Redesign

- Cancer care in the US is suboptimal with some patients not receiving care at the right place or time
- Our health care system is fragmented has barriers to how patients access care
- Care is not coordinated across the care continuum
- Resources are inefficient and mechanisms to currently provide care can often be redundant or missing

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Hassett, MJ, et al. (2014).

Patient Experience

Interactions	Culture	Perceptions	Continuum of Care
The orchestrated touch-points of people, processes, policies, communications, actions, and environment	The vision, values, people (at all levels and in all parts of the organization) and community	What is recognized, understood and remembered by patients and support people. Perceptions vary based on individual experiences such as beliefs, values, cultural background, etc.	Before, during and after the delivery of care

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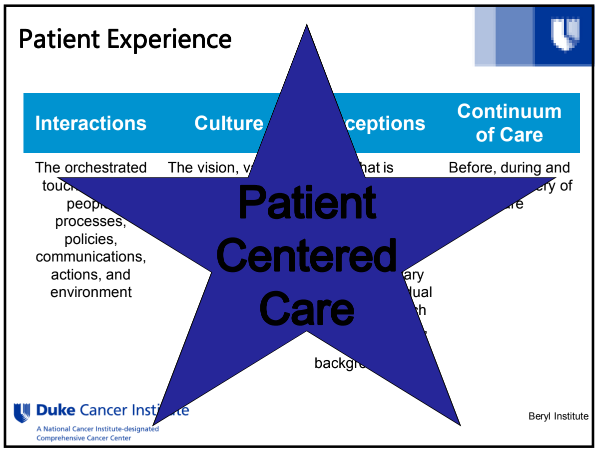

Patient Experience

Interactions	Culture	ceptions	Continuum of Care
The orchestrated touc peop processes, policies, communications, actions, and environment	The vision, v	hat is ary ual h backgro	Before, during and ery of re

Patient Centered Care

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DISTRESS IN CANCER

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Risk for Distress

- Advanced disease
- Age
- Comorbid disease
- Depression/suicide attempt
- Gender
- Long-term symptoms (cognitive impairment, fatigue, pain & anxiety)
- Poor prognosis
- Psychiatric disorder
- Substance abuse
- Other…

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Holland JC, et al. (2013). *JNCCN*, 11. Schilli, S. (2014). *CJON*, 18(6).

Screening Tools

- Anxiety Thermometer
- Anger Thermometer
- Beck Depression Inventory (BDI)
- Brief Symptom Inventory 18 (BSI-18)
- Colored Complaint Scale
- Depression Thermometer
- Emotion Thermometer
- General Health Questionnaire (GHQ)
- Global Severity Index (GSI)
- Help Thermometer
- Hospital Anxiety and Depression Tool (HADS)
- Impact Thermometer
- Kessler-10 (K-10)
- Mood Thermometer
- NCCN Distress Thermometer
- Patient Health Questionnaire (PHQ-9)
- Psychological Distress Inventory (PDI)
- Questionnaire on Distress in Cancer Patients – SF
- Screening Inventory for Psychological Problems (SIPP)
- Visual Analog Scale (VAS)

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Carlson LE, et al. (2010). *JCO*, 30(11); Schilli, S. (2014). *CJON*, 18(6).

Patient Understanding of Their Illness and Expectations

- 60 patients with advanced cancer receiving RT for symptomatic metastases
  - 35% believed that their cancer was curable
  - 20% expected that that palliative RT would cure their advanced cancer
  - 38% believed that palliative RT would prolong their life
  - 35% had concerns about the effectiveness of RT
  - 33% had concerns about the side effects of RT
  - 87% were not familiar with the concept of RT
  - 78% did not receive prior information on RT
  - 85% not satisfied with information provided by the MD

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Chow, et al. (2001). *Clin Oncol*, 13.

Prevalence of Distress

Disease site	Mean depression	Mean anxiety	Mean hostility	Mean GSI	% positive cases
Breast	52.65	55.68	49.60	53.38	32.8
Colon	52.58	53.48	49.16	52.85	31.6
Prostate	51.87	52.40	48.88	52.48	30.5

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Zabora, et al. (2001). *Psycho-Oncology,* 10.

Our 2006 Pilot

- Setting – radiation oncology
- Planning – clinic staff, APNs, & admin
- Mapping tool to the "who"
- Results
  - 57 patients
  - 31 females; 26 males
  - Brain, breast, H&N, lung, GI, GU, GYN, & lymphoma
  - Range 0-10, mean 2.2
  - 8↑; 11↓; and others same
  - Referrals SW incremental 9, counselors incremental low, chaplain 1
- Pilot debriefing with staff
- Education
- Full implementation


Table 1. Problems Noted on the National Comprehensive Cancer Network Problem Checklist

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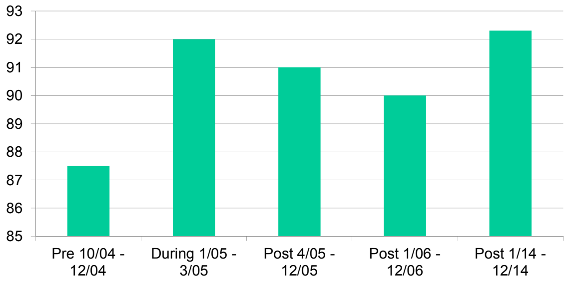
Fulcher CD & Gosselin TK. (2007). *CJON,* 11(6).

How satisfied our you with our sensitivity to your needs?



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Fulcher CD & Gosselin TK. (2007). *CJON,* 11(6).

Oncology Nursing Needs

- Survey of 401 oncology nurses
- Tools to support patients
  - 90% booklets and pamphlets
  - 78% written guides for talking providers
  - 75% individual counseling
  - 74% support staff to help guide
- Resources
  - 89% community
  - 88% peer support groups
  - 87% financial aid
  - 86% home health aide
  - 86% appearance counselor
- Healthcare providers
  - 91% dietitians, 88% SW, 87% pastoral/spiritual care


Table 2. Instruments and Approaches Used to Identify and Assess Patients' Psychosocial Needs

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Gosselin TK., et al. (2011). *ONF,* 38(6).

Oncology Nursing Needs con't

- Primary Responsibility - 35% nurse, 33% SW, 9% APN, 7% behavioral health
- Only 27% knew of the IOM report
- Inpatient and outpatient differences
- Barriers
  - Lack of time
  - Patient and family not wanting to address
  - Crisis mode
  - Lack of insurance

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Gosselin TK., et al. (2011). *ONF,* 38(6).

P5-15-11. The Distress Screening Tool: Initial Experience with Electronically Curated Patient Reported Measures

S. Power, I. Stashko, R. Blitzblau, R. Greenup, J. Horton, K. Westbrook, G. Kimmick, K. Blackwell, J. Peppercorn, G. Georgiade, R. Scheri, P.K. Marcom, E.S. Hwang
Duke University Medical Center and Duke Cancer Institute

Background

Background: In June 2013, our health system transitioned to an electronic medical record (EMR) which included collecting patient quality of life data at each clinic visit. We used the NCCN distress thermometer (DT-**Figure 1**), a short, simple to use, self-report measure which uses a 10-point scale from 0 (no distress) to 10 (extreme distress) as well as an associated problem checklist which queries the source(s) of their distress. Among our breast cancer clinic population, we studied the severity and sources of distress as well as whether the DT score was associated with stage at diagnosis and time interval since diagnosis.

Figure 1. NCCN Distress Thermometer

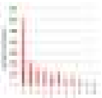
Materials & Methods

Methods: Between June 1, 2013 and October 31, 2014, starting at the time of implementation of a comprehensive EMR, all patients seen at our tertiary breast cancer clinic were asked to complete the DT survey at each clinic visit. DT data were collected and entered into the EMR at point of care. The DT tool was correlated with demographic and tumor information from a prospectively curated electronic datamart.

Results

Results: We collected 13479 DT surveys from 5261 unique patients over 17 months. Median age of the cohort was 61 years; 73% were white and 21% were black. Among those with a available staging data and a diagnosis of breast cancer, stage distribution was 41% stage I, 25% stage II, 29% stage III and 5% stage IV. The median reported distress score was 1.0 (range 0-10) with score distribution shown in Figure 2.

Figure 2. Distribution of Distress Screening Scores, from lowest (0) to Highest (10) distress



Results

The most commonly reported source of stress was fatigue (8.4%) followed by pain (6.9%). There was no significant correlation between overall distress score and stage at diagnosis. Among patients reporting distress scores of 9 or 10, the most prevalent sources of physical stress were fatigue, sleep problems, and pain; the most prevalent sources of emotional distress were worry, nervousness, and fears (**Figure 3**). The causes of distress differed between those with Stage I and Stage IV disease, with the former more likely to report pain. The most commonly reported treatment-related source of distress was neuropathy, reported by 12% of women with stage IV disease (**Table 1**). Fatigue was the most common symptom in both early and advanced stage disease.

Figure 3. Sources of Distress in Patients Reporting Highest Emotional Distress Scores

Table 1. Most Prevalent Sources of Distress Reported Among Early and Advanced Stage Patients

Discussion and Summary

Conclusions: The transition to an integrated EMR system has allowed collection of measurable patient reported data at point of care. This provides a powerful and efficient opportunity to understand the most prevalent sources of patient concerns and to identify opportunities for effective intervention. This process will facilitate the design of automated clinic workflow to identify those patients reporting greatest distress and to implement early evaluation and aid.

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Hoffman BM, Zevon MA, D'Arrigo MC, et al.: Screening for distress in cancer patients: the NCCN rapid-screening measure. Psychooncology 13 (11): 792-9, 2004.

Carlson LE, Waller A, Mitchell AJ: Screening for distress and unmet needs in patients with cancer: review and recommendations. J Clin Oncol 30 (11): 1160-77, 2012.

Hegel MT, Moore CP, Collins ED, et al.: Distress, psychiatric syndromes, and impairment of function in women with newly diagnosed breast cancer. Cancer 107 (12): 2924-31, 2006.

Hegel MT, Collins ED, Kearing S, et al.: Sensitivity and specificity of the Distress Thermometer for depression in newly diagnosed breast cancer patients. Psychooncology 17 (6): 556-60, 2008.

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DISTRESS IN BONE MARROW TRANSPLANT

Longitudinal Adaptation to the Stress of BMT

- N = 101 patients undergoing auto and allo transplantation
- 9 measures – anger, anxiety, depression, uncertainty, symptoms, personal control, body image, HC provider support, family support, friends support & coping strategies
- Timing – before BMT infusion, 7 days, 14 days, and at 1, 3 & 12 months
- Outcomes
  - Greatest emotional distress occurred after admission to the hospital and before the bone marrow infusion
  - Anxiety and depression decreased one week after transplant, while symptoms increased
  - Least emotional distress 3 months and 1 year post
  - Personal control most strongly and consistently associated with emotional response
  - At 12 mos. those with high symptoms had worse AADU scores and same with those with avoidance coping

Fife, BL., et al. (2000). *JCO*, 18(7).

Assessment of Psychological Distress in Prospective Transplant Patients

- N = 50 potential transplant patients (coordinator ratings as well)
- Measures – NCCN Distress Thermometer (DT) & HADS
- Timing – pre transplant
- Outcomes
  - 50% reported clinically significant emotional distress
  - 51% reported clinically significant anxiety
  - 20% reported clinically significant levels of depression
  - Moderate agreement between patient and coordinator ratings

Track PC, et al. (2002). *Bone Marrow Transplantation*, 29.

QoL and Difficulties of Patients

- N = 67 patients undergoing stem cell transplant
- Measures – European Organization for Research & Treatment of Cancer (EORTC) QLQ Core 30, Long-term BMT Recovery Questionnaire, and an adapted tool from the Bush BMT Inventory
- Timing – mean time since transplant 16.1 months (range 4-43)
- Outcomes
  - Younger patients poorer scores
  - Female patients lower scores in functioning and global health and higher symptom scores
  - Most frequent symptoms – fatigue, dental problems, & hair loss
  - 82% rated their global health and QoL as good to excellent
    - 59.7% reported that their current QoL was better than before transplant
    - 16.4% reported that their QoL was unchanged or worse

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Kav S., et al. (2009). *J of BUON*, 14.

Validation of the Distress Thermometer with BMT Patients

- N = 491 patients
- Measures - NCCN DT, State Trait Anxiety Inventory, ECOG PS, and Center for Epidemiological Studies – Depression Scale (CES-D)
- Timing - pretransplant
- Outcomes
  - Acceptable accuracy when compared to the CES-D
  - Cutoff score of 4 found to have the greatest sensitivity
  - Patients above 4 with worse ECOG scores and more practical, family, emotional, and physical problems

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Ransom S. et al. (2006). *Psychooncology*, 15(7).

Screening for Psychosocial Risk in Pediatric Cancer

- Of 127 COG institutions
  - 62.5% offer families services
  - 9.3% indicated a specific standardized approach
- Parents at risk for distress
- Two approaches for pediatric screening
  - Distress Thermometer
  - Psychosocial Assessment Tool (parent report)
  - Social-cultural-religious; economic; educational; medical (SCREEM)*
  - Beck Youth Inventory II*
- Screening tools are available and appear to be acceptable to families

Selove R., et al. (2011*). Pediatr Blood Cancer*; Kazak AE, et al. (2012). *Pediatr Blood Cancer*, 59(5).

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Children's Emotional Adaptation to Parental BMT

- N = 61 children ages 10-18
- Measures – Mental health subscale of the CHQ-CF87, Response to Stress, Self Esteem Subscale, Family Environment Scale, and Positive & Negative Affect Schedule
- Timing – before transplant, during parent hospitalization, 1, 4, 8 and 12 months post BMT
- Outcomes
  - Greatest emotional vulnerability was before hospitalization and the actual transplant
  - Disengaged coping was consistently associated with negative emotional response
  - More positive adaptation associated with less family role and structure change
  - Greater family cohesion and lower levels of conflict = less emotional distress
  - Emotional adaptation more negative with mother

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Spath ML, et al. (2013). *Bone Marrow Transplant*, 48.

Screening for Religious/Spiritual Struggle

- N = 178 patients undergoing transplant
- Measures - electronic self report assessment – cancer (ESRA-C), Rush Religious Struggle Screening Protocol, EORTC QLQ-C30, PHQ-9, and Pain
- Timing – first week of transplant work up
- Outcomes
  - 18% potentially experiencing a R/S struggle
  - 17% with no R/S struggle requested a chaplain to visit
  - 65% did not want a chaplain to visit
  - R/S struggle not reported in SW assessment
  - R/S struggle more likely in those who were recently diagnosed, male, and Asian/Pacific Islanders
  - ≤ 6 mos. post dx more likely to have a potential R/S struggle

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King SDW, et al. (2013). *Support Care Cancer*, 21.

Risk Factors for Depression in Patients Undergoing HCT

- N = 192 patients undergoing hematopoietic transplant
- Measures – Symptom Distress Scale, EORTC QLQ-C30, Numerical pain scale, and PHQ-9
- Timing – before conditioning and first visit post HCT (6-7 weeks)
- Outcomes
  - At T1 rates of depression were low 6% and at T2 increased to 31%
  - T1 depression score remained a predictor of poorer emotional functional
  - Depression at T2 was associated with poorer emotional functional and greater symptom distress
  - Nonsignificant trend associated with being employed or in school

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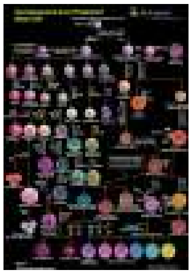
Artherholt SB, et al. (2014). *Biol Blood Marrow Transplant*, 20.

Distress, Problems, and Supportive Care Needs of Auto or Allo SCT



- N = 248 patients undergoing auto or allo SCT
- Measures – Distress Thermometer
- Timing – 0 to 1 year, 1 to 2.5 years, and 2.5 to 5 years post transplant
- Outcomes
  - Distress highest at 1 to 2.5 years
  - Top symptoms at each time point included fatigue, being out of shape/condition, and muscle strength
  - Risk factors for distress
    - Allo – female, younger, no partner, shorter time after transplant and GVHD
    - Auto – male, younger, comorbids, and time after transplant

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Braame AMJ, et al. (2014). *Bone Marrow Transplantation*, 49.

High Prevalence of Distress in Patients After Allogeneic HSCT

- N = 41 patients undergoing HSCT
- Measures – Generalized Anxiety Disorder (GAD-7), PHQ-9, Fear of Progression (FoP-Q-SF), and PTSD Checklist
- Timing – mean time post transplant was 614 days (range: 25-2070)
- Outcomes
  - 27% had moderate symptoms of anxiety
  - 27% had significant symptoms of depression
  - 29% had fear of progression
  - 15% had significant symptoms of PTSD
  - 44% distressed in at least one category
  - 56% not distressed
  - Younger patients with significantly more fears of progression

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Hefner J., et al. (2014). *Bone Marrow Transplantation*, 49.

Psychosocial Distress Screening: Application of the Oncology Standard to HCT

- Reviewed the literature
  - PubMed 2009-2014 led to 41 relevant abstracts
  - 16 screening tools
- Developed implementation plan
  - Selected Distress Thermometer
  - Developed tailored referral plans to tool
  - Goals
    - Design a standard process for psychosocial distress screening
    - Determine average score of pilot participants
    - Provide appropriate resources and/or referrals
- Outcomes
  - Completed 20 patient and 9 caregivers screens
  - Patient mean score = 3.9 (range 0-8); caregiver mean score = 3.6 (0-8)
  - Patient refs 46 total, mean 2, range 0-4; Caregiver refs 20, mean 2, range 0-3
  - Staff 100% positive PDS rating, 100% agreement that prgm addresses needs

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Foster J., et al. (2015). *Biol Blood Marrow Transplantation*. 21(2), Suppl1. Abs 587.

NOW WHAT…

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Fear of the Unknown

> *It's not so much that we're afraid of change, or so in love with the old ways, but it's the place in between that we fear…it's like being between trapezes. It's Linus when his blanket is in the dryer. There's nothing to hold on to."*
>
> M. Ferguson

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Overcoming Barriers to Practice Change

Barriers to Practice

- Use short summaries
- Incorporate user's into guideline development
- Use communication links
- Ask respected leaders to champion
- Provide incentives
- Use information technology
- Offer feedback
- Use a communications professional
- Discuss at multiple venues
- Pilot
- Feedback

Changing Behavior

- Opinion leaders and clinical champs
- Endorsement by key groups
- Educate patients
- Practice visits
- Provide education materials
- Seminars and conferences
- Reminder systems
- QA and data feedback
- Local adaptation and incorporation
- Local involvement in evaluation
- Incentives

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Omery, 2014

Where Do Your Capabilities Reside?

- Resources
  - *What can we do?*
  - High quality
- Processes
  - Patterns of how we do what we do
  - Formal & informal
- Values
  - Clear, consistent, & permeates
  - Priorities

Christensen & Overdorf, 2000

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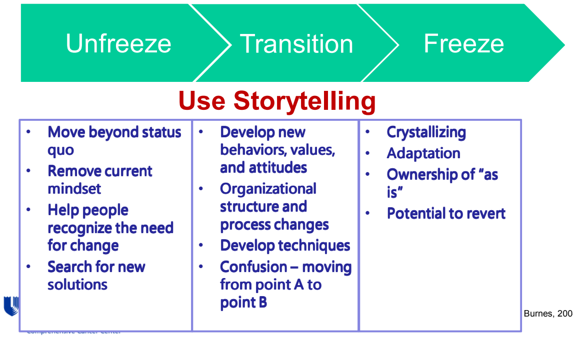
Comprehensive Cancer Center

Lewin's Change Management Theory

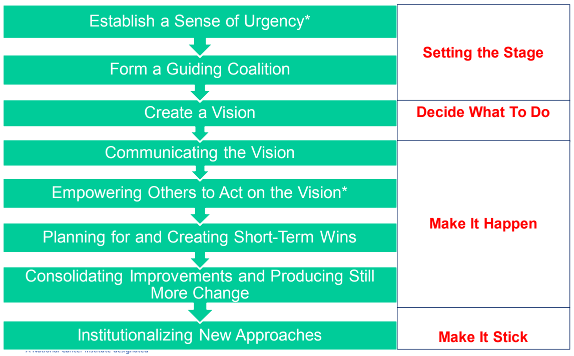


Use Storytelling

Unfreeze	Transition	Freeze
Move beyond status quo Remove current mindset Help people recognize the need for change Search for new solutions	Develop new behaviors, values, and attitudes Organizational structure and process changes Develop techniques Confusion – moving from point A to point B	Crystallizing Adaptation Ownership of "as is" Potential to revert

Burnes, 2004.

Kotter's Eight Steps of Change



Establish a Sense of Urgency*	Setting the Stage
Form a Guiding Coalition	
Create a Vision	Decide What To Do
Communicating the Vision	Make It Happen
Empowering Others to Act on the Vision*	
Planning for and Creating Short-Term Wins	
Consolidating Improvements and Producing Still More Change	
Institutionalizing New Approaches	Make It Stick

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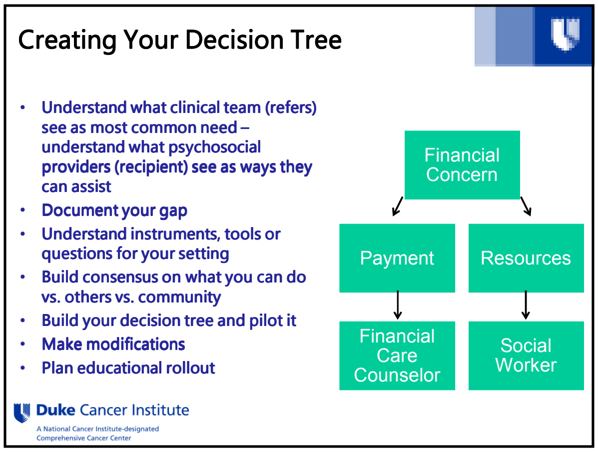
Kotter, 1995; Kotter& Rathgeber, 2005.



Creating Your Decision Tree

- Understand what clinical team (refers) see as most common need – understand what psychosocial providers (recipient) see as ways they can assist
- Document your gap
- Understand instruments, tools or questions for your setting
- Build consensus on what you can do vs. others vs. community
- Build your decision tree and pilot it
- Make modifications
- Plan educational rollout

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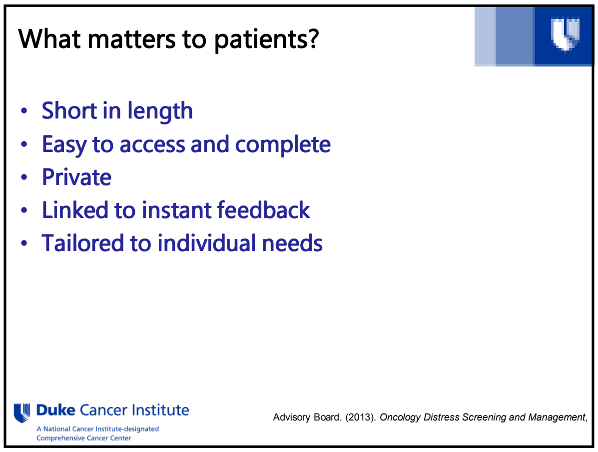

What matters to patients?

- Short in length
- Easy to access and complete
- Private
- Linked to instant feedback
- Tailored to individual needs

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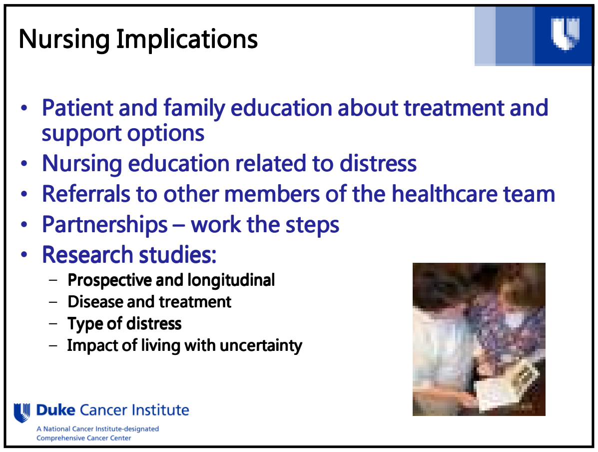
Advisory Board. (2013). *Oncology Distress Screening and Management*,



Nursing Implications

- Patient and family education about treatment and support options
- Nursing education related to distress
- Referrals to other members of the healthcare team
- Partnerships – work the steps
- Research studies:
  - Prospective and longitudinal
  - Disease and treatment
  - Type of distress
  - Impact of living with uncertainty

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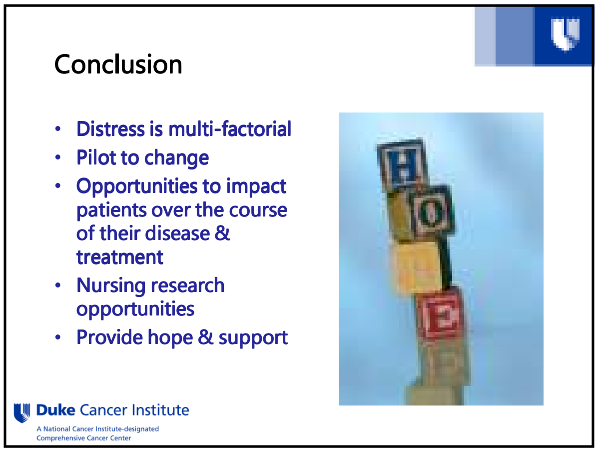

Conclusion

- Distress is multi-factorial
- Pilot to change
- Opportunities to impact patients over the course of their disease & treatment
- Nursing research opportunities
- Provide hope & support

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